Prevalence and disabilities of community-living seniors who report the effects of stroke

Corinne Hodgson, MA, MSc

Abstract

Background: Stroke is a leading cause of death and adult neurological disability. However, there are few data from which to determine the prevalence of stroke in Canada or the well-being of those who have been affected by stroke. The objective of this study was to determine the prevalence of stroke among Canadians aged 65 and over living in the community, and to explore characteristics such as the prevalence of physical and cognitive disability and the need for assistance with activities of daily living.

Methods: Secondary analysis of data from the National Health Population Survey (NPHS) conducted by Statistics Canada (1994/95).

Results: Of 58 439 people surveyed, 319 reported having experienced the effects of stroke. From these figures it was extrapolated that there are 205 000 survivors of stroke in Canada, and 4.1% of people aged 65 and older in the community are living with the effects of stroke. Seniors who experienced stroke more often reported their health to be "poor" or "fair" than seniors who had not (69% v. 25%, $p < 0.05$) and reported other health conditions such as heart disease, hypertension and diabetes. Of those who experienced stroke, 87% reported a restriction in the activities of everyday living, compared with 37% of those who had not experienced stroke ($p < 0.05$). More stroke survivors than people who had not experienced stroke reported other conditions, such as pain that prevented some or most of their activities (36% v. 11%, $p < 0.05$), mobility problems (42% v. 10%, $p < 0.05$) and cognitive problems (21% v. 11%, $p < 0.05$). Survivors of stroke were also more likely to receive home care (35% v. 9%, $p < 0.05$) and to require assistance with activities of daily life.

Interpretation: Analysis of the NPHS made it possible to estimate the prevalence of stroke among Canadians aged 65 or older who live in the community with the effects of stroke. Although cause could not be established, stroke in this age group was associated with more disability, more restrictions in the activities of daily life, poorer health and more concomitant health problems than in those without stroke.

Résumé

Contexte : Les accidents cérébrovasculaires (ACV) sont parmi les principales causes de décès et d'incapacité neurologique chez les adultes. Il existe toutefois peu de données permettant de cerner la prévalence des ACV au Canada ou de connaître l'état de santé des personnes qui ont été victimes d'un ACV. Cette étude avait pour objectif d'établir la prévalence des ACV chez les Canadiens de 65 ans et plus qui vivent dans la communauté et d'explorer des caractéristiques comme la prévalence des incapacités physiques et cognitives et le besoin d'aide dans les activités de la vie quotidienne.

Méthodes : Analyse secondaire de données tirées de l'Enquête nationale sur la santé de la population (ENSP) de Statistique Canada (1994–1995).

Résultats : Des 58 439 personnes interrogées, 319 ont déclaré avoir vécu les effets d'un ACV. On a calculé à partir de ces chiffres que le Canada compte 205 000 personnes qui ont survécu à un ACV. Les personnes âgées ayant été victimes d'un ACV affirment que leur état de santé est «médiocre» ou «moyen» plus souvent que les personnes âgées qui n'ont pas subi d'ACV (69 % c. 25 %, $p < 0,05$) et elles signalent aussi d'autres problèmes de santé comme une cardiopathie, l'hypertension et le diabète. Parmi les personnes qui ont été victimes d'un ACV, 87 % ont signalé avoir des restrictions dans les activités de la vie quotidienne, comparativement à 37 % des personnes qui n'en ont pas subi d'ACV ($p < 0,05$). Les personnes qui ont survécu à un ACV ont été plus nombreuses que les autres à signaler d'autres problèmes, comme la douleur, qui les empêchent de se livrer à une partie ou à la plupart de leurs activités (36 % c. 11 %, $p < 0,05$), des problèmes de mobilité (42 % c. 10 %, $p < 0,05$) et des problèmes de cognition (21 % c. 11 %, $p < 0,05$). Les personnes qui ont survécu à un ACV étaient aussi plus susceptibles de recevoir des soins à domicile (35 % c. 9 %, $p < 0,05$) et d'avoir besoin d'aide dans les activités de la vie quotidienne.

Special Supplement

Supplément spécial

Ms. Hodgson is an adviser with the Heart and Stroke Foundation of Ontario, Toronto, Ont.

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Interprétation : L'analyse de l'ENSP a permis d'estimer la prévalence des ACV chez les Canadiens de 65 ans et plus vivant dans la communauté avec les effets d'un ACV. Même si l'on n'a pu établir de lien de cause à effet, on associe les ACV subis par ce groupe d'âge à un pourcentage plus élevé d'incapacité, de restrictions des activités de la vie quotidienne, de mauvaise santé et de problèmes de santé concomitants que chez les personnes qui n'ont pas subi d'ACV.

Stroke is a leading cause of death in Canada. However, as the number of fatalities decreases, the number of survivors of stroke increases. It is generally accepted that only 20% of stroke survivors require institutionalization and that most (up to 80%) eventually return to their homes.[1] However, the number of stroke survivors living in communities in Canada is not well documented; estimates to date have been extrapolations from American rates and studies. As well, there is little or no information on how well stroke survivors fare in the community in terms of their health, ability to perform activities of everyday life and cognitive functioning.

In order to obtain such information about community-based stroke survivors, the Heart and Stroke Foundation of Ontario carried out an analysis of the 1994/95 National Population Health Survey (NPHS) Public Use Microdata Files.[2] The analysis focused on Canadians 65 years and older. When numbers permitted, responses of stroke survivors were compared with a baseline of seniors citizens not reporting stroke.

Methods

Secondary analyses were conducted of the NPHS database of Statistics Canada. A complete description of the methodology used in this survey is outlined in the NPHS Public Use Microdata Files documentation.[2] Briefly, using a multistage, stratified, random sampling procedure, 19 600 households across Canada were surveyed. In each household, one person was selected to provide detailed information for the longitudinal component of the survey. The survey included household residents in all provinces with the exception of populations on Indian reserves, Canadian Forces bases and some remote areas in Quebec and Ontario.

Of the 18 342 possible respondents 12 years of age or older, 17 626 participated, resulting in a selected-person response rate of 96.1%. From each respondent, information about all household members was obtained. The household response rate was 88.7% and resulted in a sample of 58 439 respondents.

Because the incidence of stroke increases with age (approximately two-thirds of all strokes occur in patients over the age of 65 years), much of the analysis concentrated on those 65 years of age and older. Information was gathered from 3143 respondents, who described 5302 people in this age group.

The complex sampling design of the NPHS posed specific problems for analysis because the survey's design and selection probabilities affect the estimation and variance calculation procedures that should be used. Thus, procedures outlined in the Microdata manual were followed in order to establish the coefficient of variation (CV) for all estimates, including estimates of percentages and of differences between percentages, to calculate confidence intervals (CI) for estimates, and to test hypotheses (*t*-tests for differences between proportions).

According to the release guidelines, estimates with a CV up to 16.5% are considered "unqualified," meaning that they are applicable for general unrestricted release, dissemination or publication. Estimates with CVs between 16.5% and 25.0% are "qualified," meaning they can be considered for general release, but should be accompanied by a warning cautioning users about the associated high sampling variability. In keeping with the Microdata manual instructions, estimates with CVs above 25.1% were not published in this report.

As recommended by Statistics Canada, all population estimates were rounded to the nearest 100. Percentages were rounded to the nearest whole digit and were accompanied by 95% CIs.

"Stroke survivors" were defined as people who identified themselves as having the effects of stroke ("Do you have the effects of a stroke as diagnosed by a health professional?"). There was no physical examination or contact with a health professional to verify self-reports. Of the 58 439 people in our sample, 319 reported having the effects of stroke.

Variables that were examined in this study include the following:

- *Health status*. Respondents were asked, "In general, how would you describe your health?"
- *Concomitant health problems*. Respondents were asked if they had any of a list of specific long-term health conditions diagnosed by a health professional.
- *Restriction in activities of everyday life*. Statistics Canada identified people as having some restriction in activities of everyday life if they answered "yes" to any of the following: "Because of a long-term physical or mental condition or a health problem, are you [is he or she] limited in the kind or amount of activity you [he or she] can do at home, at school, at work, in other activities such as transportation to or from work or leisure-time activities?" and "Do you [does he or she] have any long-term disabilities or handicaps?"
- *Mobility*. This attribute grouped respondents into the following categories: no mobility problems; mobility problems/no aid; problems/mechanical support; problems/cannot walk; and not stated. For the purpose of this analysis, "problems/cannot walk" and "problems/mechanical support" were considered to represent the presence of a mobility issue.
- *Cognition*. Respondents were grouped into the following categories: no cognitive problems; no memory problems; some-

what forgetful; difficulty thinking; and very forgetful/unable to remember. For the purpose of this analysis, the "difficulty thinking" and "very forgetful/unable to remember" categories were considered to represent cognitive problems.

- *Need for assistance*. Respondents were asked a series of questions to determine whether they required the assistance of another person with the activities of everyday life. These questions were: "Do you need the help of another person in preparing meals?/shopping for groceries or necessities?/doing normal everyday housework?/doing heavy household chores?/personal care?/moving about inside the house?/none of the above?"
- *Home-care services*. Respondents were asked "Have you received any home-care services in the past 12 months?" Respondents were then asked to individually identify the type of services received: nursing-care services (including VON); housework services (including homemaker and home care); personal-care services; meal-preparation services; shopping services; other home-care services.

Results

Prevalence and demographics

Of the total sample of 58 439 people, 319 reported having the effects of stroke. From these figures, a population prevalence of community-based Canadians living with the effects of stroke was extrapolated to be 205 000, close to two-thirds of whom are aged 65 or older (128 500/205 000 = 63%). Among community-based Canadians 65 years of age or older, 4% reported the effects of stroke (95% CI 3% to 5%).

Table 1 summarizes the characteristics of Canadians 65 years or older, as extrapolated from the survey results, who do and do not experience the effects of stroke. Of the 128 500 seniors with stroke, 68 800 (54%, 95% CI 44% to 64%) are men. Half of those with stroke (68 900 or 54%, 95% CI 43% to 65%) are between the ages of 65 and 74 years. Approximately one-third (37 600 or 29%, 95% CI 21% to 37%) are in the lowest or lower-middle income levels. Half (64 400 or 50%, 95% CI 40% to 60%) live with a spouse or partner. There were no statistically significant differences between seniors who reported stroke and those who did not in any of the demographic variables listed.

Health status

Among the Canadian population of stroke survivors 65 years or older, as extrapolated from the survey, 88 700 or 69% (95% CI 60% to 78%) feel that their health status is "poor" or "fair," which is almost 3 times as many as seniors without stroke (774 900/3 117 200 or 25%, 95% CI 23% to 27%). This difference was unqualified and statistically significant (CV of difference = 9.9%, $t = 10.0$, $p < 0.05$).

Table 2 documents the frequency with which seniors with and without stroke report other long-term health conditions. More seniors with stroke than without stroke report other health conditions. These differences were statistically significant ($p < 0.05$) but due to high sampling variability, the CVs of difference were either qualified or unreportable.

Restriction in activities of everyday life and physical disabilities

Again, using weighted numbers for the Canadian population of seniors who have had a stroke, 112 200 or 87% (95% CI 82% to 92%) experience a restriction in the activities of everyday life. In contrast, of the 3.1 million seniors without stroke,

Table 1: Characteristics of stroke-affected and nonaffected Canadians 65 years and older*

	Reporting effects of stroke *n = 128 500*		Not reporting effects of stroke *n = 3 117 200*	
Characteristic	No.	% (and 95% CI)	No.	% (and 95% CI)
Sex				
Men	68 800	54 (44–64)	1 328 100	43 (41–45)
Women	59 700	46 (37–55)	1 789 100	57 (55–58)
Age group, yr				
65–74	68 900	54 (43–65)	1 987 200	64 (62–66)
≥ 75	59 600	46 (47-55)	1 130 000	36 (34–38)
Income				
Lowest or lower middle	37 600	29 (21–37)	753 800	24 (23–25)
Middle, upper middle or highest	87 700	68 (59–77)	2 199 600	70 (68–72)
Living arrangement				
Living alone	39 800	31 (22–40)	983 800	32 (30–34)
Living with spouse or partner	64 400	50 (40–60)	1 576 000	51 (49–53)
Living with spouse or partner and children	Unreportable†	Unreportable†	262 800	8 (7–9)
Other	Unreportable†	Unreportable†	265 200	9 (8–10)

Note: CI = confidence interval.
*Weighted population and percentage estimates (unweighted n = 319). All estimates unqualified (coefficient of variation < 16.5%).
†Sampling variability so high because of small numbers that Statistic Canada does not permit their release.

1 167 500 or 37% (95% CI 35% to 39%) have a restriction. This difference was unqualified and statistically significant (CV of difference 5.8%; $t = 17.3$, $p < 0.05$).

With regard to pain, 46 000 or 36% of seniors affected by stroke (95% CI 26% to 45%) have pain that prevents some or most of their activities, as opposed to 349 800 or 11% (95% CI 10% to 12%) of those without stroke. This difference was statistically significant ($t = 5.2$, $p < 0.05$) but qualified (CV 19.1%).

Approximately 53 300 or 42% of stroke-affected seniors (95% CI 32% to 52%) cannot walk or require mechanical assistance in order to walk. In contrast, only 316 500 or 10% of the 3.1 million nonstroke seniors (95% CI 9% to 11%) have this type of limitation in mobility. The difference between the 2 groups was unqualified (CV of difference 15.1%) and statistically significant ($t = 6.7$, $p < 0.05$).

Cognitive problems

Approximately 27 400 of the 128 500 seniors with stroke (21%, CV 17.9%; 95% CI 13% to 28%) experience cognitive problems in that they have difficulty thinking, are very forgetful or are unable to remember. Among seniors without stroke, 355 800 or 11% (95% CI 10% to 12%) experience the same cognitive problems. Because the estimate of stroke survivors with cognitive problems was qualified, the difference between stroke and nonstroke seniors was not tested for statistical significance.

Home care and assistance with activities of daily life

Of seniors with stroke, 44 500 (35%, 95% CI 26% to 44%) receive home care, as opposed to 289 600 or 9% (95% CI 8% to 10%) of nonstroke seniors. This difference was statistically significant ($t = 5.6$, $p < 0.05$), although the CV of the difference was qualified (CV 17.8%). Because of the relatively small proportion of seniors who receive home care, it was not possible to obtain reliable estimates on the use of different types of services given to those with and without stroke.

Table 3 compares the need for assistance with 6 activities of daily life of stroke and nonstroke seniors. All proportions in all categories were unqualified except for 2 categories for stroke survivors: moving inside the house and personal care. For all 6 activities, more stroke survivors require assistance than their nonstroke peers. When stroke and nonstroke proportions were compared by means of a *t*-test, all 6 were statistically significant ($p < 0.05$). At the same time, however, with the exception of shopping (for which the CV of the difference was unqualified at 14.2%), the CVs for the differences were qualified.

Discussion

Stroke is a leading cause of death in Canada and is often cited as the leading cause of adult neurologic disability. Unfortunately,

Table 2: Health conditions of stroke-affected and nonaffected Canadians 65 years of age and older*

	Stroke-affected seniors *n = 128 500*		Nonaffected seniors *n = 3 117 200*	
Condition	No.	% (and 95% CI)	No.	% (and 95% CI)
Diabetes	39 900	31 (22–40)	323 400	10 (10–10)
Hypertension	58 700	46 (36–56)	871 200	28 (26–30)
Heart disease	53 000	41 (32–50)	487 500	16 (15–17)
Urinary incontinence	16 800	13† (7–13)	114 400	4 (3–5)
Arthritis or rheumatism	71 500	56 (46–66)	1 241 000	40 (38–42)

Note: CI = confidence interval.
*Weighted population and percentage estimates (unweighted n = 319).
†Qualified estimate (16.5% < coefficient of variation [CV] < 25.0%). All other estimates are unqualified (CV < 16.5%).

Table 3: Level of assistance required for activities of daily living by stroke-affected and nonaffected Canadians 65 years of age and older*

	Stroke-affected seniors *n = 128 500*		Nonaffected seniors *n = 3 117 200*	
Activity for which assistance is required	No.	% (and 95% CI)	No.	% (and 95% CI)
Moving inside the house	22 500	17† (10–24)	64 700	2 (1–3)
Housework	52 300	41 (31–51)	363 400	12 (11–13)
Heavy housework	82 000	64 (53–75)	767 400	25 (23–27)
Shopping	57 700	45 (35–55)	313 000	10 (9–11)
Preparing meals	40 500	32 (23–41)	181 000	6 (5–7)
Personal care	31 400	24† (16–32)	106 100	3 (2–4)

Note: CI = confidence interval.
*Weighted population and percentage estimates (unweighted *n* = 319).
†Qualified estimate (coefficient of variation > 16.5%). All other estimates are unqualified.

however, accurate, quantitative information on the number and characteristics of Canadian stroke survivors is limited.

To obtain more information, the Heart and Stroke Foundation conducted a secondary analysis of the NPHS general use data files. However, there are several limitations to these data. First, the survey did not ask respondents to specify time of onset of stroke or disabilities, or cause. This information would have been useful since pre-existing disabilities or other concomitant medical problems may be responsible for at least a proportion of the disability reported by stroke survivors.[3] In the Perth Community Stroke Study[4] for example, 19% of subjects had been disabled before the onset of their stroke. Thus, this limitation of the data precludes the establishment of cause and means that all associations must be interpreted cautiously.

Second, the number of people with stroke captured by the NPHS was relatively small: 319 of 58 439 people. Thus, estimates for this group have wide sampling variability, making comparisons between people with and without stroke difficult.

Third, the wording in the NPHS survey questions may have affected the number of people identified as having stroke. Respondents were asked if they had "the effects of stroke as diagnosed by a health professional." It is not clear how those who had recovered completely would respond to this question. Also, the accuracy of the claim that the stroke was diagnosed by a health professional or the validity of the diagnosis were not verified. Thus, the validity of the resulting estimates is unknown. At the same time, the inclusion of the qualifier "as diagnosed by a health professional" may have reduced errors resulting from overreporting stroke.

To date, most estimates of the population prevalence of stroke have been extrapolated from American data. Mayo,[5] for example, calculates that applying the American prevalence of stroke (0.8%) to the population of Canada produces an estimate of 208 000. Applying this same rate to the current Canadian population estimate of 30.2 million would increase the figure to approximately 241 600.[6]

From the NPHS data, the number of stroke survivors of any age living in the community was estimated to be 205 000. Almost two-thirds (63%) of these people were 65 years of age or over. This concentration of stroke among seniors was expected; 76.1% of hospital separations with a diagnosis of cerebrovascular disease are of people 65 years of age or older, as are 90.0% of cerebrovascular-related deaths.[7,8]

To calculate the total number of all stroke survivors in Canada, the number of people living in institutions must be estimated. Statistics Canada estimates that 22% of institutionalized adults 65 years of age or older have had a stroke.[9] With approximately 256 000 Canadians 65 or older living in long-term care facilities, it can be estimated that at least 56 000 are stroke survivors.[10] Adding this estimate (56 000) to the NPHS data estimate (205 000) yields a baseline estimate of 261 000 total stroke survivors in Canada.

However, this estimate of 261 000 should be taken as a lower limit, because the number of institutionalized stroke survivors who are younger than 65 years of age (albeit probably very small number) have yet to be identified. In addition, this figure does not include victims of multi-infarct dementia, who are often identified as having "vascular dementia" and may even be misdiagnosed as having Alzheimer's disease.[11]

What is the quality of life for Canadian survivors of stroke? This analysis suggests that stroke is associated with a number of health concerns and issues. Up to 70% of seniors who reported stroke described their health as only "poor" or "fair," which was more than twice as many as nonstroke seniors who indicated the same health status (69% v. 25%, $p < 0.05$). There was also a consistent trend for other health problems to be reported more frequently by stroke survivors than their nonstroke peers. Some of these (heart disease, hypertension and diabetes) are important risk factors for stroke and thus may have contributed to its occurrence.[12] Others, such as arthritis, are probably independent of the stroke and may be more related to the age of the respondents than to their stroke status.

Perhaps the biggest difference between seniors who did and did not report stroke can be seen in terms of restrictions of the activities of daily life. A previously published analysis of the NPHS data[13] shows that, among Canadians aged 55 and older, those who reported the effects of stroke are 4 times more likely to need help with one or more activities of daily living (odds ratio [OR] = 3.71, $p < 0.01$) and 5 times more likely to have 1 or more physical limitations (OR = 4.66, $p < 0.01$).

In our analysis, significant proportions of seniors who reported stroke experienced restrictions to activities of everyday life, mobility problems and pain that prevented some or most activities. Furthermore, although the estimate was qualified, approximately 20% of stroke-affected seniors had difficulty with thinking or memory. It should be noted that stroke can cause, contribute to or coexist with dementia. According to current estimates in the medical liturature, stroke increases the risk of dementia by a factor of 9.[14]

An expected outcome of the limitations and disabilities reported by stroke survivors is their greater need for assistance with the activities of daily living. When seniors with and without stroke were compared, 4 times as many stroke-affected seniors required assistance with their shopping and 3 times as many with housework. Furthermore, although both estimates were qualified, it appears that up to 8 times as many stroke survivors as nonaffected seniors require assistance moving inside the house (17% v. 2%) and with personal care (24% v. 3%). These high levels of need for assistance may explain the fact that 4 times as many stroke survivors report receiving home care than nonaffected seniors (35% v. 6%, $p < 0.05$).

In summary, this analysis of the NPHS data was conducted to determine the prevalence of and characteristics common to community-based survivors of stroke 65 years of age and older. It is hoped that this article will inspire further research, particularly of stroke survivors. Such research is necessary to compile the type of detailed information necessary for health care and social-service providers, policy analysts and families.

References

1. Bonita R. Epidemiology of stroke. *Lancet* 1992;339:342-4.
2. *National population health survey, 1994-95. Public use microdata files*. Ottawa: Statistics Canada; 1996. Cat no 82F001XCB.
3. Delaney GA, Potter PJ. Disability post stroke. *Phys Med Rehabil State Art Rev* 1993;7:27-42.
4. Anderson C, Jamrozik K, Stewart-Wynne E. Physical disability after stroke in the Perth Community Stroke Study. *Clin Exp Neurol* 1990;27:121-4.
5. Mayo NE. Epidemiology and recovery. *Phys Med Rehabil State Art Rev* 1993;7: 1-25.
6. *Population projections for Canada, provinces and territories, 1993-2016*. Ottawa: Statistics Canada; Occasional; 1994. Cat no 91-520.
7. *Hospital morbidity and surgical procedures 1993–94*. Ottawa: Statistics Canada; 1996. Cat no 82-216-XPB.
8. *Mortality — summary list of causes, 1994*. Ottawa: Statistics Canada; 1996. Cat no 84-209-XPB.
9. National population health survey: residents of health care institutions. *The Daily*. Ottawa: Statistics Canada; Oct. 27, 1995.
10. *A portrait of seniors in Canada*. 2nd rev. ed. Target Groups Project. Ottawa: Statistics Canada; 1997. Cat no 85-519-XPE.
11. Hachinski V. Preventable senility: a call for action against the vascular dementias. *Lancet* 1992;340:645-8.
12. Gasecki AP, Hachinski VC. Stroke recurrence and prevention. *Phys Med Rehabil State Art Rev* 1993;7:43-54.
13. Wilkins K, Park E. Chronic conditions, physical limitations and dependency among seniors living in the community. *Health Rep* 1996;8:7-15.
14. Erkinjuntti T, Hachinski VC. Dementia post stroke. *Phys Med Rehabil State Art Rev* 1993;7:195-212.

Reprint requests to: *Corinne Hodgson, Heart and Stroke Foundation of Ontario, 1920 Yonge Street, 4th floor, Toronto ON M4S 3E2*